

A PROPOSED MODEL LAW TO PREVENT GENETIC DISCRIMINATION

NOVEMBER 1996

I. Findings and Purpose

A. Findings-

- i)** The collection, retention, use and dissemination of genetic information can threaten an individual's right to privacy.
- ii)** Analysis of an individual's DNA provides information not only about an individual, but also about that individual's parents, siblings, and children, thus implicating family privacy.
- iii)** Improper disclosure of genetic information can lead to significant harm to the individual, including stigmatization and discrimination in areas such as employment, education, health care, and insurance.
- iv)** Genetic information is uniquely private and personal information that should not be collected or disclosed without the individual's authorization.

B. Purpose-

- i)** To protect the confidentiality of genetic information.
- ii)** To regulate the collection, retention, disclosure, or use of genetic information.
- iii)** To protect against discrimination by an insurer or employer based upon an individual's genetic information.

II. Definitions.

Genetic information is information about inherited characteristics. Genetic information can be derived from a genetic test, family history, or medical examination.

A genetic test is any medical or scientific test used to seek genetic information, including but not limited to direct DNA analysis, chromosomal analysis, or tests for the presence or absence of gene products.

An insurer is a company or a representative of a company that provides health, life, disability, or automobile insurance.

III. Use of genetic information by insurers and employers prohibited.

A. Insurance

No insurer shall:

- (a) Refuse to enroll any person or accept any person as a subscriber on the basis of a person's genetic information;¹
- (b) Determine a rate on the basis of a person's genetic information;
- (c) Offer or provide different terms, conditions, or benefits, on the basis of a person's genetic information;² or
- (d) Otherwise consider genetic information in the provision of insurance coverage or benefits.

B. Employment³

No employer shall:

- (a) Refuse to hire or employ an individual on the basis of that person's genetic information;
- (b) Bar or discharge an individual from employment on the basis of that person's genetic information;
- (c) Discriminate against an individual in compensation or in terms, conditions or privileges of employment on the basis of that person's genetic information; or
- (d) Otherwise consider genetic information in employment decision making.

IV. Mandatory genetic testing prohibited.

No employer or insurer shall:

- (a) Require or request that any individual or a member of an individual's family undergo a genetic test; or
- (b) Offer inducements for genetic testing.

¹ Based on California state law: Health and Safety Code, section 1374.7; Insurance Code, sections 101.23, 10140, and 11512.95.

² Based on California state law: Health and Safety Code, sections 1374.7, 1374.75 and 1374.9; Insurance Code, sections 10123.3, 10123.31, 10123.35, 10140, 10140.1, 10140. 5, 11512.95, 11512.96, and 11512.965.

³ The entire employment section of this model is based on sections (a) through (c) of Chapter 204 of New York state executive law.

V. Collection of genetic information prohibited.

No employer or insurer shall:

- (a) Require or request that any individual or a member of the individual's family reveal whether the individual or a member of the individual's family has obtained a genetic test, or what the results of the test were;⁴ or
- (b) Otherwise seek, receive, or maintain any genetic information.⁵

VI. Disclosure of genetic information without consent prohibited.

- (a) Genetic information, including but not limited to genetic test results, shall be confidential and privileged and shall not be released except to the individual tested and to persons specifically authorized by such individual to receive the information after prior written and informed consent.
- (b) No one may disclose genetic information of any kind without obtaining written informed consent for each disclosure. This right may not be waived.
- (c) No person may sell to or interpret for an employer or insurer a genetic test of an employee or insured person.
- (d) A general authorization for the release of medical records or medical information shall not be construed as an authorization for disclosure of genetic information. Authorizations for the release of genetic information and for any genetic test must, without exception, include specific, informed consent for each instance of disclosure and for each test performed.

VII. Enforcement and penalties: civil remedies.

A. Private right of action

Any person aggrieved by a violation of this act shall have a cause of action against the person or institution who committed such violation and may recover compensatory damages and/or equitable relief. Compensatory damages shall be in an amount equal to the actual damages suffered by the aggrieved person or \$1,000.00, whichever is greater.

If the court finds that a person or institution in violation of this act knew or should have known that such conduct was in violation of this act, the court may award up to three but not less than two times the amount of actual damages suffered by the aggrieved individual. Such action shall be brought in Superior Court.

B. Action by the Attorney General

If the Attorney General has reason to believe that a person or institution is violating or intends to violate the provisions of this act, he may bring an action in the name of the commonwealth against such person or institution to obtain equitable relief and/or damages for any individual aggrieved by a violation of this act. Such an action shall be brought in Superior Court.

⁴ Based on Wisconsin Statutes, section 631.89.

⁵ Based on California state law: Health and Safety Code, sections 1374.7, 1374.75 and 1374.9; Insurance Code, sections 10123.3, 10123.31, 10123.35, 10140, 10140.1, 10140.5, 11512.95, 11512.96, and 11512.965.

C. Penalties

If the court finds that a person or institution has inadvertently violated this act, the court may require such person or institution to pay a civil penalty of \$1,000.00 per violation.

If the court finds that a person or institution is in willful violation of this act, the court may require such person or institution to pay a civil penalty of \$5,000.00 per violation.

The court may award the reasonable costs of investigation and litigation of a violation of this act, including reasonable attorney fees.

D. Relationship to Other Laws

Nothing in this act shall be construed as limiting or prohibiting the pursuit of any other remedies available under common or statutory law in regard to genetic information privacy.